



Simple Facts About Myalgic Encephalomyelitis (ME)

Although ME is recognized as a neuroimmune disease around the world, in the US, governmental health agencies redefined ME as “chronic fatigue syndrome” and expanded the clinical definition to include patients who do not all fit the original diagnostic description. In recent years the term ME/CFS has been used to replace the term CFS.

Patients who fit the criteria for ME also fit the criteria for CFS or ME/CFS. But patients who fit the *overly broad criteria* for ME/CFS may not fit the criteria for ME as defined by the experts in the [International Consensus Criteria \(ICC\)](https://onlinelibrary.wiley.com/doi/full/10.1111/j.1365-2796.2011.02428.x). (<https://onlinelibrary.wiley.com/doi/full/10.1111/j.1365-2796.2011.02428.x>)

- Appears worldwide in epidemic and endemic forms.
- Chronic neuroimmune disease that affects many systems in the body including the neuroendocrine, autonomic and immune systems.
- Symptoms include: Profound dysregulation of the central nervous system (CNS) and immune system, dysfunction of cellular energy metabolism and ion transport and cardiovascular abnormalities with measurable abnormalities in physical and cognitive function.
- Defined in 1955 outbreak at London’s Royal Free Hospital and labeled myalgic encephalomyelitis.
- Redefined by CDC with overly broad criteria and renamed chronic fatigue syndrome, following cluster outbreaks in Nevada and New York in the mid 1980’s.
- 1 million men, women and children suffer with ME in the U.S. alone, 17 million worldwide.
- Majority are disabled: unable to work, attend school or participate in activities of daily life.
- 25% bedbound/housebound due to severity of symptoms, unable to care for themselves.
- Shortened 20 year life span/premature death from complications of ME.
- Frequent suicides due to the severity and length of suffering without proper palliative care, understanding from medical community, and effective treatments.
- 17 to 25 billion dollar burden to the economy.
- Cause is unknown. Suspected immune deficiencies, chronic viral/microbial infections, autonomic/sympathetic/central nervous system dysfunction and genetic factors, among others.
- No cure and no approved FDA treatments for the disease.
- NIH has underfunded research for decades. According to NIH Research Portfolio Online Reporting Tools spending in 2018 is estimated to be \$16 million and the estimate for 2019 is \$14 million . A similarly prevalent disease, HIV/AIDS receives \$3 billion. \$250 million would be equitable to similar diseases like MS.
- Negligent medical school training results in poorly and erroneously trained physicians and medical staff. Broad CFS criteria, a deficient disease description, and the recommendation of ineffective treatments comprise the curriculum if it is even taught at all. Nothing is taught on ME.
- High percentage of Chronic Fatigue Syndrome Advisory Committee (CFSAC) recommendations have been ignored by HHS. [Note: CFSAC is a federally chartered advisory committee charged with advising and recommending to the Secretary of HHS on issues relating to patient care, clinical, research and educational issues for CFS and ME.]